

Clinical Cardiac Transplantation Registry

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Cardiac allotransplantation is donor dependent therapy. Critical evaluation of relevant data within the Transplant Institution and at the national level is necessary in order to improve the effectiveness of the organ procurement, distribution and transplantation systems. A systematic gathering and analysis of data is an essential component in building a solid framework for improving cardiac transplantation and effectively using the limited organ resources.

Several national (United Network for Organ Sharing, Regional Transplant Organizations) and international (International Registry for Heart and Lung Transplantation) cooperative programs pool clinical data into their data banks. Each individual cardiac transplant center has the responsibility to capture and analyze data relative to local results. This data includes many patient variables such as demographics, history, risk factors, operative and interventional procedures, pretransplant organ function, ischemic time and preservation, immunosuppressive therapy, complications, outcome, and follow-up. This bank of information serves as a basis for analyzing clinical results in terms of risk stratification, mortality and morbidity, and survival studies. Today's personal microcomputer technology and new database software provides quick data entry, analysis, comparison, and retrieval of voluminous patient information with a minimum of computer experience. The rapid evolution of transplant science and clinical experience require a high degree of flexibility in the transplant database to include new developments, customizations and expansions. After customization data needs to be retrieved to create a file for the several programs and registries, which are continuously comparing local results and trends with national and international data.

The "TRANSCARDIAC" is a fully functional database program dedicated to cardiac transplantation including neonatal and infant patients. Data acquisition starts at the inquiry level, when an end-stage cardiac failure patient is considered for transplantation. Formal referral includes collection of historical and recent clinical and laboratory data, before the patient may be registered with UNOS. Pretransplant follow-up in the Heart Failure Clinic is also included in "TRANSCARDIAC". When a suitable transplant donor is identified his/her data is captured together with the organ procurement and the transplant

procedure data. The post-transplant follow-up will be a recipient life-time process.

Data Entry:

- Nearly 500 data fields
- Types of data definitions: text, number, date, calculations and memo fields
- Number of keys is unconditional
- Entry is easy and direct
- Types of entry: pull-down menus, pre-defined value lists, buttons, mouse-driven, keyboard-driven

Design Constraints:

- Users consist of physicians, transplant coordinators and data coordinators
- Passwords to limit access
- Validity checking (on crucial data)
- Sixty-two percent of the text fields contain a predefined value list minimizing the data entry errors and lost of critical information
- Enables queries to be defined so that data appears to users in a naturally intuitive manner
- Type of computer environments: Macintosh, Windows and networkable in both

File Maintenance:

- Files are packed and compressed to eliminate unnecessary room and empty space
- Back-up daily, weekly and monthly basis with report generations
- System performance is fast, precise and concise
- Provide integrity services to enforce database constraints; resource locking – to prevent the concurrent update problem, data that is retrieved for the purpose of update must not be shared among network users
- Must be able to recover from failure. Database must be durable and be able to survive machine failures, disk crashes and unenlightened users
- Security facilities – users do not all have equal authority

The "TRANSCARDIAC" is a transplant-oriented database designed to have meaning to allied health professionals working with computer systems and caring for cardiac transplant recipients.